DOCUMENT RESUME

ED 067 668 EC 031 528

TITLE Exceptional Children Conference Papers: Involvement of Parents in School Programs.
INSTITUTION Council for Exceptional Children, Arlington, Va.
PUB DATE 70
NOTE 77p.; Papers presented at the Northwest Regional Conference (Vancouver, British Columbia, October 29-30, 1970)

EDRS PRICE EDRS Price MF-$0.65 HC-$3.29
DESCRIPTORS *Conference Reports, *Exceptional Child Education, Institutionalized (Persons), *Parent Child Relationship, *Parent Counseling

ABSTRACT

A selection of four papers from those presented at the CEC Northwest Regional Conference (Vancouver, British Columbia, October 29-30, 1970) deals with the involvement of parents in school programs. Beryl Critchley briefly cites the area of work with parents of exceptional children while Vera Brianza details work with parents of preschoolers. Ila Gaspass considers the parents who have children in a residential school; and William Bonk examines the parental emotional response to mental retardation and professional support. Other collections of papers from the conference have been compiled and are available as EC 031 525 (Pre and Inservice Training), EC 031 526 (Social and Institutional Changes in Special Education), EC 031 527 (Administrative Procedures and Program Organization), and EC 031 529 (Teaching Strategies, Methods, and Instructional Materials). (CD)

EC031528

ED047448

Exceptional Children Conference Papers:
Involvement of Parents in School Programs

Papers Presented at the

Northwest Regional Conference

The Council for Exceptional Children

Vancouver, British Columbia

October 23-24, 1970

Compiled by

The Council for Exceptional Children

Jefferson Plaza, Suite 900

1411 South Jefferson Davis Highway

Arlington, Virginia 22202

EC 031 528

EC031528

PREFACE

Involvement of Parents in School Programs is a collection of 6 papers selected from those presented at the CEC Northwest Regional Conference, Vancouver, British Columbia, October 31 - 24, 1970. These papers were collected and compiled by the Council for Exceptional Children, Arlington, Virginia. Other collections of papers from the conference have been compiled and are available from the ERIC Document Reproduction Service. Other collections announced in this issue of Research in Education may be found by consulting the institution index under Council for Exceptional Children or the subject index under Exceptional Child Education. Titles of these other collections are:

Pre- and Inservice Training
Social and Institutional Changes in Special Education
Teaching Strategies, Methods, and Instructional Materials
Administrative Procedures and Program Organization

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Working With Parents of Exceptional Children

Beryl Gridley
Washington Association for Retarded Children, Seattle

Having worked with parents of retarded children as a Principal of a school in the Highline School District for 18 years and as Director of the King County Chapter, Washington Association for Retarded Children for 5 years, ending July 1, 1970, I have been aware of the importance of understanding the family situation as part of the total picture of working with retarded individuals.

If a retarded person is in a state residential schools, the situation becomes one of that school program and helping the family to use the best resources of the school. This is a liaison relationship.

If the individual is remaining at home for care then the relationship with the family group should be in support of that group understanding of the retarded individual and ability in making living plans for the individual. The father, as well as the mother is included, also the brothers and sisters, to recognize the retarded's limitations as well as his potential abilities.

The family should be helped to know of community facilities for religious training, health and well being of the family member who is handicapped and for all education opportunities available in the community.

WORKING WITH PRESCHOOL PARENTS

Dora Grissom
Washington Association for Retarded Children, Seattle

Parents are the most important people and prime teachers in a young child's life whether he be normal or retarded. Perhaps in the life of the mentally retarded or handicapped child education would be most in importance; education for the parent as well as the child.

Let's analyze the word education in relation to the young child. The normal child has his own sequence of development and through his own drives and curiosity learns by watching, listening, smelling, moving, imitating etc., but for the mentally retarded physically or multiple handicapped child many of these basic skills need to be taught, step by step. Therefore, because of the child's readiness - his development may come later than what is considered normal, the time for learning may be lost and so the process of learning becomes more difficult.

The preschools in King County are organized to meet the needs of these children. Some of the preschools accept children as young as eighteen months and as old as eight years. Occasionally an older child or two [illegible] where there is not a suitable public school program for them. There are no ability requirements for these preschools, each child is accepted at his own level of development. Some children need stimulation, some need to learn how to move in a group and how to take direction. Others need training in how to get along with their peers and also adults. Most of the children need to develop self-help skills, small muscle coordination and language skills. Concept learning, such as; identification classification, recognition, etc., is built into the curriculum.

The term parent participation means different things to different people.

In these parents enrolled in a Parent Cooperative Preschool, it means that a parent actually participates in the classroom on a regular schedule. This kind of program enables a consistent learning experience for the child because the parents understand the preschool program and are learning how to work with children with various kinds of handicaps.

The parents of these preschools assume a management role in the school. There is a parent board, elected by the parents and a community advisory board which consists of community people interested in the success of such a school.

A parent group meeting is planned once a month, at which time, the business of the preschool is considered. An education program follows, giving the teachers and therapists an opportunity to discuss the school program and the goals for the children for the next month. This also serves as a briefing for the parents who participate in the daily sessions.

The teachers are employed by the parents group. They are responsible for planning the preschool program. These teachers need to have special skills and patience in order to teach both children and adults.

If a parent, either mother or father, cannot participate actively in the school program, arrangements may be made for a parent substitute. This plan maintains the ratio of one adult to each two children. With volunteers assisting in the program, too, a one to one relationship may be possible for the more severely involved child.

In those parents enrolled in a Parent Participation Preschool, participation means observing regularly in the classrooms and regular conferences with the teachers. Invited volunteers help in the classrooms to maintain a ratio of one adult to each two children.

The parent group meets regularly to discuss business pertinent to the functioning of the school and to further their knowledge about their children.

These schools have differing kinds of support from the school districts, such as, a representative from the school district serving on the advisory board, psychological testing, the use of audio visual equipment, the use of space in a school building and referrals to the preschool.

Several school districts in King County have incorporated preschool programs into their regular Special Education programs. In two of these school district programs the parents participate in the classrooms as well as volunteers. They have active parent groups to further the education of the parents. These groups are organized with parent officers who are responsible for the scheduling of parents and volunteers for the preschool classes, also for the program for the parents meetings.

All of these parent groups give the parents an opportunity to meet with other parents of children with similar problems. Often when parents have just learned that their child is mentally retarded or that he is not able to function at a normal level because of his handicaps they feel so alone and in such despair, but when the child is enrolled in a preschool program and they become members of a parent group, they find kindred souls who can talk with them and understand them, not as a professional basis, but as parents, too.

Jan Hoyt, a parent of a Down's Syndrome child presented a paper before the Interstate Unit, New Jersey Parent Group for Retarded Children in April 1968, entitled "The Three Stages in the Growth of a Parent of a Mentally Retarded Child". The three stages he says are 1) the stage where one is entirely subjective, concerned almost wholly with himself and the effect that things have upon him, 2) concern primarily for the child. What resources could be tapped for the benefit of the child and 3) what can be done to help others and less of what can be done for us.

Even though this pamphlet was written in 1968 these stages for the parents still hold true. Progress has been made in diagnosis, medicine, education and community acceptance, but each parent is new to the experience of having a handicapped child and needs to work through his own emotional problems.

It is in the second stage of growth that the parents usually locate a preschool. Parents of very young retarded children are often so attached to the child, and so over protective that they find it difficult to leave the child at school, so being able to participate in the planning for the child, to express themselves to the teachers, to know the teachers personally is helpful in setting the emotional and protective ties.

To assume leadership in a parent organization helps the parents to grow, not only in leadership abilities, but also to grow in understanding of the needs of other people with similar problems. This is the third stage -- what can be done to help others. There is strength in a unity of purpose.

The child also gains from his parent's involvement in the parents group. From the education, the parents have learned, either from participating in the school or at the meetings, observing at the school and conferencing with the teachers or attending lectures, they have become more knowledgable in methods to work with their children and to handle their own problems. This should result in some follow through at home and a better home situation.

In the fall of 1967, the King County Chapter of the Washington Association for Retarded Children and the Central Health - Central Intermission Board of King County provided funds, jointly, for a preschool coordinator and consultant for the County Preschools for Retarded Children.

Previous to this time there were autonomous schools, started in various ways with various kinds of leadership -- some are twelve years old now. They were associated with the King County Chapter. When the U.S. - U.S. was formed, the preschools became a part of their program also, since the schools were already receiving funds and County funds.

I joined the King County Chapter staff to fill this newly created position. There were no guidelines to follow, as I pioneered my work from my experience on the staff of the Family Life Education Program of the Seattle Public Schools and the Seattle Community College.

I observe in the classroom, conference with the teachers regarding curriculum planning for the class as a whole or [illegible] individual child, also to help with the parents. I conference with the parents, explaining the development of the child in the classroom, making suggestions for follow-through at home, serve as a listening post for those who need to talk. I may make suggestions for further evaluation of the child. I attend some board meetings, as a resource person and attend the parents meetings to bring new information to them and occasionally give a talk on a specific subject.

I have been working through a plan to have joint parent group meetings, occasionally, this would enable the schools to have guest speakers without exhausting the time and energy of the dedicated people in this field who are willing to give of their own time. These meetings also give the parents of the different preschools an opportunity to meet together and hopefully to broaden their horizons.

It is my observation that it is important especially with the preschools actively involved with the parents, to have a resource person who is aware of the overall school program and who has a knowledge of home relations to help to work through the problems that may arise. This explains the development of communication lines between the resource person and all those participating in the preschool. This is a big order to fill and realistically can't be fully accomplished.

The Children's Orthopedic Hospital, the University of Washington, the Public Health Nurses, the Headstart Program and the Department of Public Assistance refer children to these preschools, either through or or directly to the school. Either through or the child's progress and sometimes the mother's progress and serve as a liason person between the agency, school and family.

Many of these agencies are supporting Parent Cooperative Preschools to help the mother in her understanding of the children with varying degrees of handicaps, as well as education for the child.

It has been my experience in the past year that there is better communication between the agencies. We all feel the need for coordinated efforts in finding and giving the best service possible for the individual child, in order that, he may develop to his optimum potential.

In order to plan help for the child, it is most important to plan help for the parents. Various agencies working with families of all kinds of handicapped children offer classes for parents. The subjects will cover specific problem areas - toilet training, feeding, discipline, the inclusion of the child in the home, etc.

In Volume 19, No. 5, January 1965 - The Journal of Nursery School Education printed an article by Dr. Samuel Ishoal and Dr. Edward Lehmann entitled "Early Childhood Education is Essential to Handicapped Children".

The following quotes are out of context but are supportive of the ideas set forth in this paper. Under the [illegible] of the Nursery School, the article states "Even recently, with a increased preoccupation on specific disabilities and a greater understanding of the common problems facing handicapped children, an increasing number of nursery schools are setting a variety of exceptionalities. Overall an awareness is growing in the United States of the many ways the nursery school can aid these young handicapped children." Under the heading "Comparison with other Children" the article points out the role of the nursery school teacher. It states " It seems unfortunate that it is not suggested here that the nursery teacher should act as the diagnostician or evaluer clinician. Her role is that of skilled observer. When it comes to young children she might well make observations that could assign a clinician whose contacts come from limited inquiry to a one-to-one conventional relationship. The quality of the essential records kept by the teacher will have particular importance here."

The article closes with a lengthy section namely "Close Cooperation between Parents and Nursery School, Important". The following quote is the first two paragraphs of this section."Another significant example of nursery education of the handicapped child pertains to the involvement of the parent. A good program of parent education centered on guided parent participation can have an especially salutary effect on the home situation. In terms of parent education, there is the need for the family to gain an understanding of the child's handicap and the special needs the family must be prepared to meet. At the same time the parents often may fail to understand that, the handicap notwithstanding, the child has the same basic needs as other children. Naturally, the family physician and the clinic will have given the parents some help. But the nursery school can relate this more readily to practical problems of child management of concern to the parent."

In summation it would seem to me that it can accurately be stated that educating parents is of vital importance to the young mentally retarded handicapped child.

We should consider the child and his parents as individuals, each one's needs are different, each one deserves the right to respect and to human dignity and his own uniqueness.

WORKING WITH PARENTS WHO HAVE CHILDREN IN A RESIDENTIAL SCHOOL

Ila Sampson
Seattle, Washington

The reference to a "Residential School" in the title of this presentation denotes what we now term and refer to as the typical state or provincial, congregate institution for the retarded.

Parents have different reactions upon being faced with having a retarded child. When parents find out their child is retarded it is usually a very traumatic experience. They ask "What have I done to have this happen to me", and nearly has a problem such as mine, where shall I turn?" Despite all the public understanding, the surprising how little we want to know until we are personally involved.

In the early years age, when a child was diagnosed as retarded, the only route to go was from home to institution, no other services existed. It was a frightening and horrible experience to commit a child to an institution for life, and the process was difficult. In such a long time, the conditions in the state institutions were not the best.

Today it is an accepted fact that retarded persons can be helped and should live at home as long as possible to benefit from, first, the love, understanding and help the parents can give him and from the many programs in the community. Then, he may eventually have to go to an institution to live, but at least he has had the opportunity to profit by what his family and community can give him.

Parents benefit from community programs also, in that they learn to accept the problem of mental retardation, know they are not alone, and have the satisfaction they are doing all they can to help their child.

There are many different kinds of parents with as many different kinds of needs. There is the parent who knows about mental retardation and who cares enough that he wants to help in any way he can. This parent, with proper interpretation and exposure and involvement can be enlisted into a person who will understand the total picture and can become very effective as a parent working in a voluntary organization such as the Association for Retarded Children.

There is the parent who cares and wants to help but is frightened and insecure, probably from trying to handle the problem alone. He can be helped to understand his own problem, to know what can be done for his own child and can eventually be an effective contributor in a broader sense to the total field of mental retardation.

Then of course, there is the parent who doesn't understand or doesn't care and doesn't want to get involved; the child is no longer his responsibility, yet he is the first to complain if things don't go well or he is faced with charges for care or if his child might be returned to the community. This kind of person needs to be taught the true facts and to realize his obligations both to his own child and to the total program.

Residential care should be for only those who really need it. The key to the success of residential care is in the parents understanding the institutions program in general and also the individual program for his child such as care, schooling, vocational training, social and recreational. This program may include ultimate placement in the community, in group homes, nursing homes, foster homes, or boarding homes. Hopefully, the stigma of congregate institutional care will change to one of smaller, community oriented facilities in the foreseeable future. Only in this

approach can be a positive success in normalizing the lives of the mentally retarded.

The Scandinavian countries, who have the most outstanding system of habilitation services, firmly believe that retarded persons, like normal persons, have the ultimate right at age of maturity to be rid of their parents and vice versa. With the retarded the key word is maturity but one has to ultimately accept and as a factor so that parents are not burdened with a life time responsibility. This point in life, that of maturity is when the parents have a right to assume that the community and the state, through their programs for the retarded, will assume responsibility for the adult life.

It is also important that a parent relinquish the right to decide the future of his adult or mature child, who has in the opinion of the responsible authority proven himself capable of some form of rehabilitation or return to society. So long as parents understand that the responsibility of the future of the retarded person remains with the community and state, they will not be worried that failure of the retarded person to function in the community will reure him to the parent's home.

There are many ways a parent can be involved with activities at the institutions. Parent's Clubs are popular in Washington State. A form of PTA, parents can do fund raising to provide the activities the institution budgets cannot or will not provide. Their volunteer services to the school can be invaluable. I have yet to see an institution that's has enough hands to do the regular duties, let alone the extra things that make institution living more pleasant. Meetings are held with staff to help maintain standards of good care and for the continual upgrading of the parent's knowledge of the current philosophy in the rehabilitation of handicapped persons.

At least one institution superintendent I know, doesn't feel he is yet successful in reaching the needs of parents and many parents feel they are not getting the help they need. There sometimes isn't the time or willingness on the part of the institution staff to reach out to parents on an individual basis. Yet, the primary concern is: "What about my child?". To reach out to the parent and to give some satisfaction takes a battery of forces. No one person or organization can do it. Most institutions are not set up to cope with parents on this basis.

As a parent of a retarded person in an institution, I feel we have the right to expect the best possible care and program for our children, but I also feel we have an obligation to participate in a helpful and constructive way.

I firmly believe if a parent is kept interested in the total field of mental retardation, the reasons and causes, the achievements of others, the hope for ultimate betterment of the child no matter how severe the handicap, he will be much better prepared to see the good that the institution and/or community can do for his child. He will be able to see what his child can do, rather than what he cannot do. He will understand the problems of running an institution and be able to share with other parents.

He will keep looking for answers to what is best for his child and what is best for his family. He will grow to point of helping all retarded persons to their rightful and most secure place in the community.

It is an objective we must all work toward. The institutions, the voluntary groups, the medical profession, the legislature, the educators, the employers, the clergymen and the parents all play an important part in reaching this objective.

PARENTAL EMOTIONAL RESPONSE TO MENTAL RETARDATION AND PROFESSIONAL SUPPORT

William Winnek
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The process of bringing up a child is rarely entirely pleasant, although in most families, parents would feel that the rewards of raising children more than compensate for the problems and conflicts. Ingenuity, a sense of humor, patience and understanding are required in large doses from parents of even bright and healthy youngsters. No matter how temporarily angry or disappointed they may be, the parents of normal children can maintain an atmosphere of confidence and acceptance, sustained by the belief that "everything will turn out all right."

For the family of a retarded child, the situation is infinitely more complex and difficult. For some families, it is a tragedy of serious magnitude and its effects are disillusionment, despair and disruption. To other families, it is a crisis, which although serious, is capable of resolution with time. To still others, it is not a problem in itself, but is merely one element among many in the daily struggle for social survival.

For professionals who work with the retarded child and his family, it is important to be aware of the kinds of ways parents and families respond to this problem so that we might be more sensitive in our dealings and our counseling of these families. Today, I would like to talk about these family responses and also how we as professionals might improve our techniques of support for the retarded child and his parents.

Neither mental retardation nor parenthood has the same meaning to all parents. Much depends on parental experiences during their own childhood; on their income, education and culture; on their philosophy of life and their value system; and perhaps most importantly, on the stability of their marital relationship. The appearance of the child, his degree of retardation, his behavioral patterns, the attitudes of relatives, neighbors, will all affect family adjustment. With all of the above-mentioned factors, it is obvious that there can be no standardized approach to helping these families; however, there are some recognized themes which need resolution.

Every family of a retarded child must at some time face the fact that he is mentally retarded. The circumstances surrounding this recognition may be sudden or gradual; the realization may come at the time of birth or may come after the child has been in school a few years. For almost all families, however, the truth must be faced to some degree by the time the child is 7 or 8 years old.

Most parents develop an understanding of their child's condition in a gradual and at times painful manner. Many spend a great deal of time, energy and money in a search for some more acceptable diagnosis or for a cure which never materializes. The process of acceptance seems to follow a pattern, whether it covers many years or is achieved after a single interview. One pattern occurs when the diagnosis of mental retardation is presented to unsuspecting parents. This frequently happens shortly after birth; for example, in the case of mongolism. Normal birth is very anxiety producing. Parents are usually expectant and looking forward to the birth of a healthy child. They have notions concerning the future occupation, marital status and personality of their expected child. The birth of any baby which upsets these expectations may precipitate a shock crisis which can severely disorganize the parents' adjustment since it occurs at a time of great parental vulnerability. Their dreams of the future are shattered; their sense of adequacy is shaken; and they experience a grief reaction during which, for a time, they withdraw from others to deal with their own sorrow. Although these parents may realize that their previous expectations have to be radically revised, they commonly know little or nothing concerning realistic expectations for their new baby. The parents are faced with "What is wrong - How bad is it?" in conjunction with the associated problems of their previous expectations of normality. The crucial element at this time is not the mental retardation, but the demolition of their expectancies. It is often a mistake for the professional worker to interrupt this process too quickly with reassurance and comfort. It can be even worse to offer the parents a false hope of recovery within the framework of a special class or any other therapeutic measure.

It can be helpful for the professional worker to offer information aimed at explanations that help erase the unknown aura from the child's condition. If any facts are known about the nature of the mental retardation, they should be relayed to the parents. If no facts are known about the nature of the retardation, the parents should be told this also. The crucial element here is honesty and forthrightness in helping the parents to look at the situation realistically. There is little value in making statements about the distant future. Most parents need time to adjust themselves to the tasks of the present. Long-range forecasts very often are proven wrong in that the relative speed of development is not constant for all children.

Given the opportunity, parents can sometimes be very accurate judges of their children's level of development. They bring into focus the comparisons they have already made between the retarded child and its siblings or other children of comparable age. The professional can be of help by listening sympathetically and helping the parents to interpret their observations regarding development. The professional can also help parents to understand what behaviors are most likely at the various stages of development and that certain behaviors may be prolonged because the developmental course of their child

may be ashamed. The counselor needs to prepare the parents for a mutual adventure in "life planning" and to assure them that, as far as is possible, he will be there to offer support and guidance at each milestone in their family's life.

Once parents recognize the extent to which their child is retarded, they then begin to ask questions about why this problem has happened. Two kinds of motivation seem to underlie these questions. The first is a hope that, in discovering the etiology of the disorder, they may find a way to cure it and prevent its occurrence in any future child they may have. The second reason seems to be directed at relieving a tremendous burden of guilt and responsibility which many parents are faced with. They feel that the blame for their child's handicap rests with them. Some harbor the memory of an unwanted pregnancy; sometimes there is even a deliberate attempt at abortion. The retarded child can become the focus of all past wrongdoings of which the parents feel ashamed.

In most instances, identifying the precise cause makes little difference to the child; and when future plans are being made, the etiology of the disorder does not offer much. However, answers to the questions of "Why?" do relieve anxiety in the parent and provide support at a time when the parents see themselves as being solely responsible for the tragedy. Most parents find some relief from guilt when they learn of the great number of families who share their problems, of the multiplicity of factors which can interfere with the delicate balance of normal development, and of the overwhelming likelihood that their child was damaged before birth by causes over which they had no control.

Another area of concern is the issue of acceptance of the child. Acceptance of the retarded child, as of the normal child, involves warm appreciation of his individuality, pride in his assets, and tolerance for his shortcomings. It may be unacceptable to some parents that although a son may not have the potential to become a successful merchant or professional, he may become self-supporting at unskilled or semi-skilled work. The accepted child has a smoothly functioning role in the family setting. With retarded children, this goal is difficult to attain, but not impossible. The retarded child can be viewed as an intruder, and his relationship with his family is fraught with frustration, guilt, anger and fears which make for serious barriers to his healthy integration in the family group. In mild instances of rejection, the retardate is treated with ambivalence and overprotection. In severe forms, rejection can lead to early institutional placement and denial of the retardate's existence.

Many factors are involved in a parent's ability to adjust to the situation of having a retarded child. It would seem that the parent's strengths, his personal value systems, his economic circumstances and the particular needs of the child are among the important considerations. If the professional can help the parents

to clarify their own personal value system and how this relates to their acceptance of their child, the situation can sometimes be improved. At times, exploration with the parents around the possibility that their child possesses certain attributes which the parents can appreciate is a first step towards helping the parents learn acceptance.

When the professional is evaluating families and feels that nonacceptance of the child is a crucial issue, it is important for the worker to remain integrated into the family or community. A mother with a hyperactive child, in a family of several young children may not be able to meet the physical demands of caring for her retarded child. Sexual behavior on the part of the young adult retardate may be judged as being dangerous to others or unacceptable to the community even though such a situation may represent simply a value crisis for the community and may not reflect accurately the retardate's potential for misbehavior. Other environmental pressures such as death of a parent, financial pressures, or expulsion from school can raise enough anxiety and concern within the family unit so that the parent is forced to ask for relief. The handling of these crises requires that the professional be aware of the reality-based nature of the requests and be willing to try crisis intervention techniques which may or may not involve the actual removal of the retardate from the home for a short period of time. People who can be called upon to help are MARC service centers; the outpatient staff of local institutions; and the evolving university-affiliated community mental health centers and mental retardation centers.

There are some other themes which occur in families of retardates which are less easy to specifically support management techniques for, but which the professional is certain to be asked about for guidance. These include the problem of overprotection, the issue of family integration and the effect of the retardate on other siblings.

Parents may make it difficult for the retardate to learn to cope with environmental pressures if they do not encourage the maximum growth consistent with his handicap. Overprotection tends to perpetuate the child's dependence on his parents and prevents his mastering skills within his limitations. The overprotection behavior is probably determined by many factors. The busy mother may find it much easier to feed, clothe and bathe her retarded child than to allow him to go through the process himself. Whereas it may only take a few weeks of frustration with a normal youngster to help him learn to use a spoon, the same process may take months with the slow learner.

It has also been suggested that prolonged infancy and heightened dependency of the retarded child can cause the establishment of a mutually gratifying relationship. The pattern is especially difficult to change, since it has been overlearned by both mother and child. The mother may find herself in serious difficulty when she wants to train the child to follow the rules of family living.

We have mentioned before that overprotection may be a defensive maneuver to conceal rejection, hostility towards the child and the mother's subsequent guilt. The painful emotions can be softened and at times repressed if the mother exceeds the normal demands for caring for her child. The more she does for her child, the less she has to look at her own feelings of conflict and ambivalence about having a slow learner. For the professional, the success he has in helping families with overprotection depends in large degree on the neurotic overlay of the parents. If guilt and ambivalence are not excessive, support and an educational approach can be very useful in teaching the parents the importance of allowing their child to assume appropriate responsibilities.

A great deal has been said about the adverse effects of a handicapped child on the relations of the normal family members, but there is little substantial research in this area. No one would question the assumption that a retarded child places additional stress on families, but little about this process is documented.

At times, clinically, it appears that the stress of a retarded child is much like any other stress which the family might face. It may even be a lesser threat than other stressors such as chronic illness, imprisonment, or collapse of a business venture. It is also not unusual to find a healthy family in which the retarded child seems to exert an integrative effect, mobilizing the resources of family members and encouraging their psychological growth. Unfortunately, the retarded child can also become the focus of concern in a marginally adjusted family, upon which the rest of the family is able to transfer the unhealthy tensions they have been developing with each other.

In general, the presence of a retarded child is not ordinarily conducive to family integration. In fact, the retarded child can be thought of as cutting short the ordinary progression of family living patterns. Farber and his associates suggest that the presence of a moderately or severely retarded child in a family arrests the usual family cycle. The family cycle may be thought of as beginning at marriage and progressing through successive stages characterized by the age of the youngest child in the family. It is the youngest child whose dependence is the greatest and limits the behavioral choices of the parents to the greatest extent. Parents whose children are not handicapped eventually cease to have very demanding obligations to their children, who are married and who have begun their own family cycles. The markedly retarded child, who becomes psychologically the youngest child in the family, may, in contrast, never be more socially mature than the normal preadolescent; and thus, the family cycle may never progress beyond this stage. Neither parent can look forward to a time when responsibilities toward his children will have been fulfilled; occupational retirement takes on a different meaning, and arrangements must be made to care for the adult retardate after the parents are no longer capable of doing so.

Farber suggests that families in which husband and wife could achieve mutual satisfaction and gratification of their own goals fared better than did parents who lacked focused goals or whose roles impeded the achievement of their shared goals. The parents' orientation toward each other became more important when their external environment was worse.

The issue of the retarded child's effect on other children in the family is a primary concern to many families. Advice to place the child away from home in the interest of the normal children is made too routinely and often is ill-founded. Children largely reflect the feelings of their parents. If the parents are unashamed of the retarded child, the normal children are likely to be so too. Farber has also done some research into this issue and discovered that the variable which seemed of greatest importance to the siblings was the degree of dependence of the retarded child; that is, how much he was able or permitted to do for himself. The more dependent the child, compared with other retarded children his age, and the younger he was, the more adverse was his effect on his siblings. This means that it was not the presence of a retarded brother or sister, but the amount of responsibility assumed by the normal siblings, which was the adverse factor. The evidence seems to suggest that most children can adapt themselves to the presence of a retarded brother or sister and that they tend to adopt the attitudes of their parents toward the family situation. Only when they are pushed aside or expected to assume maturity and responsibility beyond their years are they likely to suffer consequences.

Lastly, I would like to give some general pointers for professionals:

1. TELL the parents the nature of the problem as soon as possible. Parents are often concerned just as early as their practitioner, but are afraid to put their fears into words. It is important to be honest and straightforward as soon as one can.

2. Always see both parents. Both parents should be present whenever possible. Both need to be guided together in understanding and acceptance.

3. Watch your language. Parents need to understand the implications of their problem, but do not need to be bombarded with professionalese or words which are obnoxious.

4. Help parents see that the problem belongs to them. Don't take the problem over from the parents. Decisions such as placing the child in an institution have to be made ultimately by parents and although professionals can help in counseling, we should not take away responsibility of parents in such major matters. Parents get a great deal of unsolicited advice from many well-meaning people--neighbors, friends, relatives--and when the professional is able to help the parents to see the problem belongs to them, they can close their ears to the advice and rely on their own judgment.

5. Parents need help in understanding the problem. No matter how much a parent may read, they usually still have unanswered questions. They continue to need support.

6. Don't put parents on the defensive. All parents make mistakes in raising children. Parents who have retarded children will make errors, but should not be made to feel guilty about them.

7. Remember the importance of the professional's attitude towards parents. It is important to empathize and to help parents feel we understand the difficulties they have and are having.

8. Try to learn as best you can the resources available in your area.